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ABSTRACT

As agencies and programs serving individuals with developmental disabilities are called upon to serve a new population of individuals with human immunodeficiency virus (HIV) infection, they will be forced to confront complex legal questions. This paper discusses the legal frameworks in which individuals with HIV infection are considered eligible for developmental services. Legal cases and statutory frameworks which serve as the basis for disability policy are summarized. The legal implications of HIV infection for service providers are discussed, focusing on access to services, education, child welfare and residential services, segregation of services, HIV testing, informed consent, confidentiality, records, duty to warn, and liability. (JDD)

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Technical Report on Developmental Disabilities and HIV Infection

HIV Infection Legal Issues: An Introduction for Developmental Services

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Introduction

As of February 6, 1989, approximately 85,590 individuals have been diagnosed with AIDS in the United States. The full designation of AIDS is guided by the Center for Disease Control (CDC) definition which includes the presence of special opportunistic infections accompanying HIV isolation or antibodies in the person's blood. An earlier and milder expression of HIV involvement is referred to as "AIDS-Related Complex" (ARC) or symptomatic HIV infection. Currently, 1.5 million people are estimated to be asymptomatic HIV carriers. These people have positive anitbody tests, indicating an encounter with the virus but do not yet have identifiable illness. It is estimated that, by 1991, there will be 270,000 cases of people diagnosed with AIDS in the U.S.—a figure that threatens to overwhelm health and social services.

In addition, the Public Health Service has predicted that there will be 3,000 cases of pediatric AIDS by 1991, while HIV could infect 20,000 children by that year alone. Adding to the already 36 million people in the United States with disabilities, it has been estimated that in the next five years, HIV may become the largest infectious cause of mental retardation and encephalopathy in children under age thirteen.

As developmental services are increasingly called upon to serve a new population of infants, children and adults with HIV infection, programs will be forced to confront complex legal questions. This paper will discuss the legal frameworks in which the individual with HIV infection may be considered in developmental services. Some issues are left unresolved because of uncertainty about the applicability of disability law to HIV infection. Although not a comprehensive analysis of legal statutes, this paper serves generally to introduce the appropriate legal frameworks as well as give references for further inquiry.

Developmental Services

Services for persons with developmental disabilities have grown and developed over a 20-year history. Originally prompted by federal legislation, these services have developed into a complex array of federal and state programs that serve persons with developmental disabilities. Three major components have developed from federal law: basic state council grants (DDC), university affiliated programs (UAP), and protection and advocacy systems (P&A). Basic state grants fund DDCs for planning and service improvement activities; UAPs conduct research and provide service programs; and P&As work to protect the legal rights of people with disabilities under federal and state statutes.

Federal law under Section 504 of the Rehabilitation Act of 1973 defines handicap as "(1) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (2) has a record of such an impairment, or (3) is regarded as having an impairment."

Developmental disabilities are further defined by the 1978 Developmental Disabilities Act [29 U.S.C. 706(7)] as chronic and attributable to mental and/or physical disabilities which are evident prior to age twenty-two. These disabilities tend to be life-long and result in substantial limitations in three or more of the following major life activities: self care, receptive and expressive language, learning, mobility, self-direction, the capacity for independent living and/or economic self sufficiency. Some groups that fall within this definition include people with mental retardation, cerebral palsy, epilepsy, other related neurological conditions, and infants and adults with HIV related diseases who meet the above mentioned criteria.

The following service programs are considered in the context of this paper: habilitative, rehabilitative, social services, health care, and education.

HIV Infection and the Law

Legal developments in the area of HIV infection began to emerge over the past three years. The following legal cases and statutory framework serves as the basis for disability policy, as well protection and remedies for persons with disabilities who are HIV infected.

Section 504 of the Rehabilitation Act is the most important protection mandate used in preventing discrimination by institutions that receive federal financial assistance. Section 504 states:

> No otherwise qualified handicapped individual in the United States, as defined in [29 U.S.C. 706(7)]..., shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance or under any program or activity conducted by an Executive agency or by the United States Postal Service.

After initial questions about the applicability of Section 504 to AIDS, on March 3, 1987, the U.S. Supreme Court decided in *School Board of Nassau County v. Arline*, a case involving a teacher with tuberculosis who was fired because she was infec-

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tious, that a medical condition caused by an airborne infectious agent could be considered a handicap, and rejected the Department of Justice's opinion that discrimination could be lawful if it was based on fears deriving from the handicap's contagious nature. The Court explicitly rejected the analysis of the Department of Justice and reaffirmed the protections of Section 504 for people with contagious diseases. This decision was widely held to apply to asymptomatic and symptomatic HIV infection, and AIDS.

On December 1, 1988, the Eleventh Circuit Court of Appeals in a case involving a child with developmental disability and HIV infection, *Eliana Martinez vs. School Board of Hillsborough County, Florida*, effectively set up a framework for how P.L. 94-142, the Education of the Handicapped Act, and Section 504 of the Rehabilitation Act, work together in cases involving children with a contagious disease and another disability. The decision in the Martinez case set up a process whereby a determination was made about the most appropriate educational placement under EHA procedures and, next, a determination of whether the child is otherwise qualified in the meaning of Section 504, as determined by the prior test case of Arline, to be educated in this setting, despite the communicable disease. If not, the court must decide whether reasonable accommodations would reduce the risk of transmission so as to make the child otherwise qualified to be educated in the least restrictive environment.

The Civil Rights Restoration Act of 1987 overturned the Supreme Court's decision in *Grove City College v. Bell*, 465 U.S. 555 (1984), a case involving federal education aid to a student at Grove City College and whether this deemed the entire institution responsible for antidiscrimination provisions. The Court decided that federal education aid had a limited definition on the term "program or activity" as mentioned in four federal statutes that bar discrimination by institutions receiving federal financial assistance. The Civil Rights Restoration Act overturned this decision and expanded the definition of program or activity to include an entire institution.

The Fair Housing Amendments of 1988 protects, for the first time, discrimination in housing outside the public sector, for all private individuals and entities, not simply on the part of those individuals or entities. (Section 504 only applies to entities receiving federal money.) This bill protects all people with disabilities—including AIDS—from discrimination in sale, rental, or terms on conditions of sale or rental of housing.

The Hill Burton Act provides uncompensated care obligations for persons residing in the local area of a hospital that received federal loan guarantee and interest subsidies for construction. These hospitals can be challenged for discrimination in certain circumstances.

On October 6, 1988 the Department of Justice (DOJ) issued a memorandum acknowledging that the Supreme Court in Arline rejected the Department's argument that discrimination based on fear of contagion was not covered under Section 504. DOJ went on to state, for the first time, that people with asymptomatic HIV infection were covered under Section 504, as contrasted with full-blown AIDS. This opinion will impact on existing and future federal programs and policies as well as state statute interpretations.

The Education of the Handicapped Act, discussed more in depth in the section on education, provides remedies for ensuring appropriate educational services for all children with disabilities.

Other state and local laws have provisions that further define handicapped individual, provide remedies for discrimination, and regulate and monitor developmental services. Under state and local laws, the definition of handicapped individual depends on wording of the laws, legislative histories, and administrative and judicial interpretations. State and local jurisdictions are not bound to follow federal law, except where an institution receives direct federal monies or instances of housing now protected under the Fair Housing Act. It appears that many states do extend their handicapped laws to prevent discrimination based on HIV status.

In a recent survey by the State AIDS Policy Center at George Washington University, all states but Alabama have existing anti-discrimination provisions for the handicapped. Twenty-six states have extended these protections for persons with AIDS, and symptomatic and asymptomatic HIV infection. Twenty-three states have extended protections to those perceived to have HIV infection. A drawback, however, is that most laws apply only to employment. Housing and private firms were often left out.

Legal Implications of HIV Infection and Developmental Services

Access to Services

Ironically, the service system that is in place to serve persons who are disabled, in some cases, is denying services to persons with HIV for a variety of reasons, these include lack of understanding about the basic epidemiology of the disease, fear of program liability, lack of adequate education of clients and their families as well as staff, and the extreme burden placed on already inadequate resource.

Many people with HIV have had trouble in securing and paying for medical care and expenses. Many of these people lose or have no private health insurance. These persons experience eligibility requirement problems with Medicare and Medicaid that include waiting periods that may outlast their health, requirement of a definitive diagnosis of AIDS excluding less serious HIV conditions, or may be above the income and assets eligibility, but are also disabled and unable to work.

These issues are not new to persons with developmental disabilities who may already be qualified for benefits under Supplemental Security Income (SSI) and Supplemental Security Disability Income (SSDI) programs, with accompanying Medicare and Medicaid health care support services. As a result, persons with developmental disabilities may not experience the problems mentioned above; however, in many instances, obtaining quality and readily available medical care and other services for persons with disabilities has been an issue for decades, especially with the onset of deinstitutionalization and increasing competition for resources between institutions and community providers. HIV illnesses further complicate these problems.

Physicians and other service and medical treatment professionals are ethically bound to provide treatment to persons with developmental disabilities and HIV. The American Medical Association and the American Bar Association Journal have stated that AIDS patients are entitled to competent medical service. The American Bar Association's AIDS Coordinating Committee (1988) writes:

> Professional ethical obligations may become legally enforceable obligations if they constitute the standard of care against which professional regulatory boards or

juries deciding malpractice claims measure a provider's conduct (p. 72).

Developmental services are guaranteed for persons with developmental disabilities under an array of federal and state statutes, some of which are mentioned in this paper. Some persons needing developmental services will be disabled and meet the federal developmental disability definition as a result of HIV infection, and others will be increasingly disabled from HIV infection and have an existing developmental disability.

Section 504 of the Rehabilitation Act is currenly being applied in cases of denial of health care access in various health care settings (see *Doe* v. *Centinela Hospital*, No. CV-87-2514-PAR, C.D. Cal. 1988).

Denial of services by a professional who undertakes treatment of any person, regardless of whether they have HIV infection may also be remedied under tort principles of law. Professional malpractice may be constituted by proving that the defendant owed a duty to provide treatment, that the defendant breached the standard of care, that the plaintiff was damaged, and that the defendant's breach caused damage (ABA AIDS Coordinating Committee, 1988). Tort principles may apply to any developmental service system that does not provide services to appropriately qualified individuals, or outside service organizations who refuse treatment of an individual with HIV and a developmental disability.

Education

The Centers For Disease Control has been active in providing guidelines for children with HIV in school settings. Several school systems throughout the country have been caught in divisive debate about attendance of children with HIV, including special education classes and pre-school day programs for children with HIV and developmental disabilities. Some school systems have cited state laws on contagious diseases as grounds to justify exclusion.

The Supreme Court decision of 1954: *Brown v. Board of Education*, (347 U.S.C. 483), described the role of public education as a right "which must be made available to all on equal terms". The Education of the Handicapped Act of 1975, P.L. 94-142, assures a free, appropriate public education for all children with handicaps. The definition under this Act includes the presence of a named disability, and requirement that the child need special education and related services. P.L. 99-457, Part H, the Handicapped Infants & Toddlers Program, also extends special education services to infants and toddlers ages 0-2 with a known developmental disability or, at each state's option, to those at-risk of a disability. Pre-school children from ages 3-5, who have a diagnosis of physical or mental condition which results in developmental delay are mandated services under this law.

Some children with HIV infection will not meet the definition of developmental disability under P.L. 94-142 in the early stages of infection, but may fulfill this definition as the disease progresses and they experience mental and physical deterioration. Children with another disability and HIV, and children with HIV from birth who experience central nervous system dysfunction and developmental disability do fall within the scope of this Act and this law is successfully being used to litigate on behalf of children with HIV. In the course of P.L. 99-457, an unresolved question is whether states will include HIV positive status as fulfilling the "at risk" designation under Part H of that legislation, thereby warranting services.

Section 504 of the Rehabilitation Act has been a successful nondiscrimination statute used in school systems and among the general population that have denied access to HIV infected children as well.

A major challenge facing the disability field is to consider the concepts of least restrictive environment and normalization or mainstreaming, in the face of immense pressure to educate children with HIV infection in "different settings". This may result out of well-intentioned rationalizations or also unfounded fear and hysteria.

Child Welfare and Residential Services

The child welfare system and residential services for children and adults with developmental disabilities has yet to confront HIV infection in a systematic fashion because of the relatively low numbers of infants, children and adults with HIV infection served to date. However, as the number of cases rises, similar issues regarding testing, confidentiality and access to services will emerge.

To legally conduct an HIV blood test of infants, children and adults with HIV who are wards of the state, i.e., foster, care or state institutions, the same procedures discussed more in depth later in this paper apply here. An HIV blood test may be conducted by permission of a legal guardian or by the agency with custody petitioning the Court. It appears that the state does have jurisdiction over these matters in foster care situations, but the ABA AIDS Coordinating Committee reports that no state has taken that position, as of this writing.

The Child Welfare League of America Task Force on Children and HIV Infections (1988) reports that no major medical or professional group has called for mandatory testing of children in the welfare system. However, some medical groups have asked for waiver mechanism that will allow testing of infants and children without applying the informed consent procedures.

The CDC in its Mortality and Morbidity Weekly Report (1985) states that child welfare agencies may want to consider mandatory testing and that adoptive and foster parents may need to know HIV status in order to provide medical care. Many child welfare agencies are following case by case situations regarding HIV infection.

Difficult questions remain unresolved concerning who should be informed of HIV status. Is an agency liable for not informing prospective adoptive parents that a child has HIV infection? Do these parents have the right to know? Should employees and other parents of children with HIV infection in foster care, group homes, and day care programs be informed of a child's HIV status? Should physicians freely share information about HIV infection and patients among themselves and with other care providers?

The Child Welfare League of America (1988) has developed policy guidelines for child welfare agencies that include residential services. The policy states that no child should be denied placement and that agency staff and care-givers should be told of the child's HIV status on a "needs to know" basis. The policy goes on to state that foster care parents and adoptive parents should be informed of the child's HIV status.

Segregation of Services

Issues around segregated services have emerged in facilities

and institutions where clients with HIV infection are separated from the general population, and in community residential services based on non-compliant behavior. As issues that are similar to denial of access to services, these issues may be resolved utilizing similar provisions in Section 504 of the Rehabilitation Act, Fair Housing Act, Civil Rights Restoration Act, and the Education of All Handicapped Children Act. However, attempts at justifying more restrictive service delivery will have be carefully monitored and based on only the latest medical information and legal principles.

Resolution of these issues will also depend on state laws and regulations of facilities, administrative rulings and knowledge about HIV transmission as determined from the latest scientific expertise.

ADDITIONAL QUESTIONS - People with developmental disabilities already have complex service needs that include medical, educational, residential and habilitative services. HIV further complicates these service needs. Infants with HIV infection grow up with developmental disabilities and, according to the progression of HIV disease, meet the federal definition of having a developmental disability, thereby mandating that DD services be afforded them.

Are anti-discrimination laws adequate to address the service needs of the individual with HIV and a developmental disability?

Are funding sources adequate to cover the additional medical and social service costs of this population?

What is the most appropriate method for ensuring that the individual with HIV infection and a developmental disability does not infect others while continuing to provide needed services?

When is it appropriate to qualify a child with HIV infection as a child with a handicap under P.L. 94-142? When is it appropriate under P.L. 99-457 to determine when an individual is "at risk"?

When, if ever, is it appropriate to segregate an individual with HIV infection in community residences and institutions?

Can welfare agencies mandatorily test infants and children for HIV infection and who gets informed of the results?

HIV Testing

In addition to child welfare agencies, states have jurisdiction over testing in state institutions and facilities since they traditionally fund, manage or regulate these services. State laws differ on mandatory, routine and voluntary HIV testing of persons in facilities and programs serving persons with developmental disabilities; however, some states have specifically passed legislation that disallows HIV antibody testing without expressed informed consent of the individual or guardian. Most states rely on testing in facilities based on medical indications or known risk behavior.

Related issues apply to the institutional prison system where the federal government and some states have started mandatory testing requirements in order to uphold the view that HIV carriers need to be identified in order to protect the uninfected population and prisons workers.

Others argue that, if universal precautionary measures are adhered to and admission procedures assess risk for exposure to HIV and other diseases while providing education to institutionalized persons, staff and families about contagious diseases, then mandatory HIV antibody testing is unwarranted. These persons also cite concerns about breach of confidentiality and civil rights.

Issues regarding mandatory HIV antibody testing without informed consent in developmental services is largely unresolved in state courts. Some states are considering specific legislation on this matter while others are relying on past procedures. Clearly, while there are no precedents, some programs are testing without client or family knowledge, as has been brought to the attention of several state P&A agencies. Many ethical and legal issues remain to be resolved.

However, in some individual cases in the private sector, Section 504 of the Rehabilitation Act is being used to resist demands to inappropriately conduct mandatory HIV antibody testing.

Informed Consent

For persons who are minors or have mental disabilities, obtaining informed consent has traditionally relied upon family members who are legal guardians, or a court determination that the person is not competent to make their own decisions. The court can grant permission for substitute decision making for all or some life decisions including major medical treatment, residential status and freedom to exercise other rights.

Informed consent among persons who lack decisional capacity—which may be the case with the adult who has a developmental disability—has always been a difficult issue for courts to handle and there is little guidance on these issues. These issues are also directly relevant to minors where the parents serve as the natural guardians.

The presence of HIV infection increases the complexity of these issues. Behaviors that may have been accepted in certain individuals with developmental disabilities could increase the pressure to restrict their liberty and involve substitute decision makers when considering HIV. Other rights to choose certain activities, especially in matters relating to sexuality, become difficult to manage and could result in rights violations.

Developing appropriate mechanisms to provide substitute decision making in these areas will be increasingly complex. As outlined by Sundram (1988), New York has implemented with some success, volunteer committees that are enpowered to make decisions about medical care of persons who lack decisional capacity. The law protects physicians from liability when they rely on the committee's decisions.

When a client is admitted to a facility in the developmental disability system, that facility usually routinely conducts medical exams and blood tests. The law does not require that expressed consent be granted for every procedure; however, much controversy has resulted over informed consent and the HIV antibody test.

ADDITIONAL QUESTIONS - Issues regarding mandatory, routine or voluntary HIV antibody testing in facilities and programs serving persons with developmental disabilities are largely unresolved. The following questions need to be considered.

Is it ever appropriate to test for HIV antibodies without the client or legal guardian's informed consent?

Should facilities be allowed to mandatorily test clients? Are there differing criteria for community service providers?

How should pre- and post- test counseling be handled for the person with a developmental disability? How is the client's family involved in this process?

Confidentiality

Rights of persons with disabilities must be balanced with public health concerns. Traditional public health measures as well as provisions to allow protection of civil rights for persons are founded on principles of confidentiality. Breaches of confidentiality can and have led to discrimination in housing, employment, health care and public accommodations for persons with HIV, other diseases and disabilities.

Although legal recourse may be available, resources to allow individuals to undertake legal suits are often not available, and if undertaken, can be traumatic for the individual. Many public health experts believe that special confidentiality provisions through enactment of legislation are necessary to protect persons' civil rights. Congress has considered this issue but has not successfully enacted provisions.

Records

Providers of services and health care workers are obliged to maintain confidentiality of medical information about clients. These principles derive from the common law and U.S. Constitution, state statutes and facility licensure laws.

These confidentiality laws have also extended to information about drug and alcohol treatment and sexually transmitted diseases. Information about HIV status and treatment for AIDS clearly should be included in these safeguards; however, because of the irrational fear and hysteria that has accompanied AIDS, these safeguards have not always been maintained.

Medical information is disclosed when a client or guardian gives express written consent. This raises the same issues under informed consent, however, when considering how to best handle the person who lacks decisional capacity or is an infant.

Some staff members of developmental service agencies feel that in view of the special risks associated with HIV infection, that all staff and health care providers having contact with the client need to be informed. Others argue that because HIV is not casually transmitted, only immediate care providers need to be informed and that stricter confidentiality procedures should be put in place.

Duty to Warn

Considerations involving confidentiality are not absolute and courts have ruled that, in some cases, disclosure is outweighed by the need for the public good. In *Tarasoff v. Regents of University of California*, the California Supreme Court held that a psychotherapist was liable for not protecting a third party of a client against potentially dangerous acts. Hence, the duty to warn was phrased as a responsibility to warn an intended victim when a client presents the risk of serious danger to another.

In some states the duty to warn is controlled by specific state statues and other states have not ruled on Tarasoff questions. However, this legal precedent has special implications for developmental services, especially since many clients have diminished mental capacities and impaired judgement.

Tarasoff is a legal principle that some people will use to justify breaches of confidentiality and mandatory HIV antibody testing, and to warn sexual partners and potential victims of transmission; however, this principle is untried in cases involving HIV and developmental disabilities. Belitsky and Solomon (1988) write:

The duty to disclose will depend on an assessment of the patient's reliability, knowledge, and consistency in adhering to "safe sex" practices. If the physician believes that sex will be practiced safely, we believe, the presumption should be in favor of confidentiality. However, in a case where the physician's judgement is wrong and transmission occurs because the patient did not engage in safe sex, the physician may be held liable.

ADDITIONAL QUESTIONS - Confidentiality provisions present complex issues facing service programs for persons with developmental disabilities. The following questions need to be considered for further examination. In what situation is it appropriate to inform others of the HIV status of a person in developmental services?

How does the Tarasoff decision apply to situations involving a person with HIV infection and a developmental disability?

Are civil penalties sufficient for unwarranted breach of confidentiality involving developmental services?

Liability

Central to finding a facility liable for damages to a person is proving negligence. Some persons argue that if facilities do not take steps to identify clients who are suspected to have HIV infection, the facility is negligent and opening itself up to claims of liability by patients and their families who are particularly at risk for infection or who become infected. Such suits might involve a patient or staff who contracted HIV within the system, stating that the institution was negligent in preventing this transmission.

Others argue that the same objectives can be achieved through education of staff, clients and families, and the effective screening of risk behavior upon admission to the facility. In addition, these persons argue that development of specific policies on the care and treatment of HIV infection will reduce the risk of liability.

It seems that a court of a law would have difficulty in establishing exact causation of the development of AIDS, symptomatic HIV infection or asymptomatic HIV infection because of the time frame involved with the disease. Even more difficult to prove is that the system was negligent in failing to prevent the incident, especially when policy guidelines based on accepted scientific knowledge and reasonable provisions for education of clients and staff are instituted.

At the time of this writing, there have been no identified legal cases involving the negligence of a facility in preventing transmission of HIV infection in a developmental setting, though at least one suit has been brought against a hospital for such negligence.

ADDITIONAL QUESTIONS - Liability issues perhaps present the more unresolved questions regarding HIV and developmental services. The following questions need to be considered.

In what situation might a developmental service facility be held liable for HIV transmission?

Will development of policy guidelines and provision of education for staff and clients sufficiently thwart liability claims?

How will HIV infection impact on obtaining liability insurance for facilities?

Should states undertake tort reform to minimize facility liability claims for contagious diseases?

Conclusion

Of increasing concern is maintaining commitment to established disability law in the face of new issues posed by HIV for infants and children, and older persons who also have developmental disabilities. Current disability policy issues have an added perspective as considerations are made about how to best handle issues posed by HIV infection among persons with developmental disabilities, and how to treat infants and children with HIV infection while protecting civil rights.

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